

# Learning Paper on Dementia and Risk

Prepared by Prof. Charlotte Clarke  
Head of School,  
School of Health in Social Science,  
University of Edinburgh

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## Foreword

This paper is part of a series of Learning Papers commissioned by Genio to explore learnings in practice on specific topics within Dementia. This paper results from a Dementia and Risk workshop, facilitated by Prof. Charlotte Clarke and attended by representatives of Genio supported dementia projects.

This workshop provided opportunity to collaboratively explore how risk has traditionally been perceived in practice, the challenges this approach may bring to supporting the persons overall wellbeing and how a positive risk taking approach that identifies, assesses and manages risk can support safety yet not diminish a person's quality of life.

We would like to acknowledge the work of Prof. Charlotte Clarke and the valuable contributions made by representatives of the dementia projects supported by Genio.\* I would also like to acknowledge the support of Atlantic Philanthropies in funding this work.

**Elaine Howard**

**Genio Programme Manager - Dementia**

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Kinsale Community Response to Dementia (K-CORD)	Cork Integrated Dementia Care Across Settings (Cork - IDEAS)	Memory Matters Community Component
Living Well with Dementia (LWwD)	Connolly Hospital Integrated Care Pathways for People with Dementia	Community Outreach Dementia Project Leitrim (CODPL)
Community Action on Dementia in Mayo	Development of an Integrated Care Pathway for People with Dementia (DemPath)	Flourishing with Dementia (FwD)
The 5 Steps to Living Well with Dementia in South Tipperary		The Crystal Project
		There's No Place Like Home!

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## Purpose

The purpose of this Learning Paper is to describe some of the current challenges of risk assessment and risk management in dementia care, illustrating some of the evidence base. The paper draws too on the contributions of participants in a Genio workshop in Dublin in May 2015.

## 1. Understanding Risk

### Risk or Harm?

Traditionally, 'risk' has been used as a neutral term to mean the chance of something occurring, (the chance that the sun will shine today is 50%, for example). When an objective approach to risk is used, rational judgement is sought on how likely something is to happen. For example, assessment is undertaken to establish objectively how likely it is that someone will develop cancer based on a range of risk factors (history of smoking, family history etc). In this objective approach, risk may be quantified by calculating the probability (or likelihood) of a particular event occurring. Risk calculations are based on the belief that we can make objective, rational judgments (as opposed to intuition or guesswork) about whether or not an adverse event is likely to happen by calculating the event's statistical probability.

'Risk' also has connotations of 'taking a risk' (being daring or adventurous, for example). Indeed, the Department of Health for England guidance on risk management was titled 'Nothing Ventured, Nothing Gained' to convey risk as the opportunity or chance of a positive life-enhancing event (Department of Health 2010). This way of understanding risk is a more subjective approach, focusing on what risk *means* to

different people. As a result, subjective risk is influenced by culture, power, regulation and questions about 'in whose interests'. These issues are, of course, extremely important when we think about people living with dementia and their quality of life.

Neither the objective or subjective approach to risk mean something harmful, so risk and harm are not the same thing at all, although in day to day use in healthcare the term 'risk' is often used to mean harm (i.e. the terms are conflated). It is important that we separate out these two issues of risk and harm or we can lose sight of risk as the chance of a positive event.

### Risk – Person or Context?

The other thing that we need to think carefully about is the location of the risk. If we think of a person as a risk and vulnerable to harm, then our risk management tends to focus on the individual and we aim to remove them from potential harm (we may recommend that they move into a care home for example). On the other hand, if we see the environment of someone as why they are vulnerable (rather than the person inherently themselves), we can intervene by changing the environment (for example, adding security sensors to their home). It is this shift in thinking that helps policy direction change from removing people with dementia out of communities (to places such as hospitals and care homes) to creating dementia-friendly communities in which individuals are able to live in more enabling and supportive environments – a feature now of several national dementia strategies (e.g. DH 2015). By managing environments rather than seeing people as inherently problematic, people with dementia can be supported to take risks that enhance their quality of life.

Examples include the Right to Roam initiative developing in the Scottish Highlands ([www.adementiafriendlycommunity.com/?page\\_id=2715](http://www.adementiafriendlycommunity.com/?page_id=2715)), and Dementia Adventure ([www.dementiaadventure.co.uk](http://www.dementiaadventure.co.uk)) an organisation which has supported people with dementia in white water rafting among other activities that they would otherwise be 'protected' from.

## The Risks People Have

Let us look at the example of Mary and Fred who have been married for more than 40 years. Mary has a stroke related dementia which also affects her mobility and Fred looks after her. They have always lived in the same house in the same area. Recently, Fred has been struggling to get Mary upstairs to bed. Service providers are involved and provide carers to help Mary up the stairs to bed - they come around 6pm to help Mary go to bed. But the couple miss their time together in the evenings and want to stop receiving this help. They are asked to consider moving to a house more suitable to their needs but there is none in the area, so this solution is not wanted by Mary and Fred who wish to remain in their community. The third proposed solution is to move a bed for Mary downstairs. However, it is a small two-up two-down house and the bathroom is upstairs. Now there is a bed in the only living room with a commode beside it. This has a major impact on Fred and Mary's lives because they have always held card nights with friends and neighbours in their house and feel that they can't do this now, resulting in them being cut off from their community. In the end, Fred required surgery on his knee and Mary went into respite care. She never came home again and the couple were unable to live together any longer.

This is a common story, in which services proposed one 'solution' after another, but none addressed social, emotional or spiritual needs of the couple, and none actually met the needs that Fred and Mary had.

Let us look now at the risks and associated dilemmas that there are for people living with dementia as identified by the workshop participants. These can be grouped as follows:

- 1. Harms, self-neglect and antecedent activities**  
e.g. 'forgetting meals', 'driving', 'getting lost', 'leaving the house in inappropriate clothing and at inappropriate times'.
- 2. Vulnerability to the action of other people**  
e.g. 'financial exploitation', 'people taking advantage', 'vulnerable to opportunistic crime'.
- 3. Stigma and being socially isolated / excluded**  
e.g. 'loss of opportunity', 'being overlooked, not being involved in decision making', 'loss of self-determination'.
- 4. Lack of continuity of usual activities**  
e.g. 'should be supported to continue to do what they normally do', 'withdrawing from usual activities which increases isolation and reduces stimulation and wellbeing', 'loss of confidence leading to withdrawal'.
- 5. Carer unable to sustain caring**  
e.g. 'burn-out for carers and staff', 'carer anxiety'.

There are many tensions in managing risk, and Clarke et al. (2009) in a questionnaire survey of 46 managers of health, social or voluntary sector dementia services identified the following dilemmas:

- Risk and independence are irreconcilable
- The level of resource impacted on the range of opportunities to manage risk
- Ways of managing risk were influenced by the service organisation, through fear of litigation or insufficient advocacy services for example.

The study found that, in day-to-day decision making situations, the dilemmas faced by many of the respondents concerned balancing independence and autonomy with exposure to potential harm. However, maintaining safety and protection from harm is, in the view of some respondents, insufficient on its own to achieve good quality care.

In summary, the dilemmas faced by practitioners and service managers in risk assessment in dementia care are indeed complex, and profoundly influence the nature of care available to people.

## Risk – Rights and Protection

In a subsequent study, Clarke et al. (2011a) worked with 20 practitioners in a collaborative learning group to explore in depth their experiences of risk assessment and management for people with dementia. Key issues that were identified were:

- Judgements – the practitioners felt that when they made judgments, they themselves were also being judged, and this sometimes made them fearful of making decisions. They felt that they had to work with multiple views of the

‘right’ thing to do, and that gathering and interpreting information to inform judgments was complex.

- Teamworking – the practitioners described experiencing conflicting views between colleagues, between professions and between sectors. This meant that sometimes ‘problems’ were ‘pushed around’ and variously perceived to be a health problem, or a social problem, or the family’s problem, or a cultural issue, or simply someone else’s problem. We see echoes of this in the situation of Fred and Mary above.

Within these complex dynamics of judgements and teamworking, it is important to include the person diagnosed with dementia so that they can influence decisions about their own support, yet at times the voice of the person with dementia is relatively silent. Advocacy services, although rather underdeveloped in dementia care, can play a very important role to support the person with dementia be able to verbalise their needs and wishes and communicate these effectively to services (Dunning 2005). In the absence of advocacy services it is essential to ensure that the person with dementia is at the centre of all conversations and decisions.

Just as above, risks are an inherent part of day-to-day life (and are about chance, not necessarily harm), so care services too are recognising the need to move away from a position of risk adversity to recognising it as an integrated feature of services and as contributing to quality of life:

*‘Risks are inherent in social care, as in everyday life. Those leading and governing a service manage the risks in their service in a systematic way which is embedded in a culture focused on the safety, welfare and quality of life for people using the service.’ (Health Information and Quality Authority 2013, p.10)*

In this interface between human rights and protection, some of the challenges lie in managing issues such as:

- Balancing what the family want rather than what the person with dementia wants.
  - The rights of the individual can be easily lost and consideration needs to be given to where the person's voice in decision making is, especially if they have limited capacity to make and execute decisions. It is important to recognise that the wider family are living with dementia, not only the individual with the diagnosis, and that they will have their own needs and perspectives that differ from those of the person with dementia.
- Balancing entitlement to maintain an activity (such as living at home) with potential harm or living in a way that others consider to be unacceptable (e.g. lack of maintenance of the house, rats in the house, not eating properly, poor personal care).
  - If the person has the capacity to make decisions, they have a right to be supported to make a decision and be supported in executing the decision – even if others would not themselves have made that choice. It is important, therefore, to avoid any assumption that a diagnosis of dementia necessarily results in a lack of capacity and measures to improve public and care staff awareness and knowledge of dementia is essential.
- Recognising that decision making is context specific
  - It would be extremely unusual for someone to be completely unable to make a decision. For example, someone may be very able to decide what to wear each day but not have the capacity to make decisions about financial arrangements. Thus, consideration must be given to the person's awareness and ability to make decisions and the nature of decisions they can make, and assumptions that incapacity is globalised to all decisions are to be avoided.
- Recognising that capacity to make decisions will fluctuate over time.
  - It may be that someone is able to voice their preferences in the mornings when they are least tired, but by the afternoon their capacity to do so is lessened. Or capacity may fluctuate due to infection and illness. Assuming that capacity is stable over time can be very detrimental to the individual who finds people making decisions on their behalf because a period of incapacity is assumed to persist. In a study by Poole et al. (2014), clinicians were found to make decisions about capacity of people with dementia admitted to hospital with a fracture soon after admission and did not revisit their view of the person's capacity, leading to unnecessary exclusion from decisions about their treatment and future care arrangements.
- Planning ahead
  - Planning ahead means being able to support someone to make decisions about their preferences and care options when they do have capacity to do so, and to write this down for people so that their views are taken in to account even if, in the future, they do not have capacity to make decisions. This could take the form of an advance directive for example.

## 2. Positive Risk Taking and Quality of Life

If we reflect back on the statement above by the Health Information and Quality Authority (2013), they are emphasising that 'safety, welfare AND quality of life' (my emphasis) are important, not that quality of life be traded off for safety and welfare. A risk averse approach which marginalises the individual's voice and life will only serve an agenda of trading off quality of life. A risk enabling approach offers the opportunity to attend to safety, welfare AND quality of life.

Let us look at two examples in which quality of life can be compromised. The first example is an extract from a carer forum, written in response to a press release on risk management in dementia. The second example, My Mother's Baking, is written for this Learning Paper to illustrate the subtle ways in which quality of life can be undermined.

*'My mum, while she still had some mental capacity, said to me:*

*So what if I go out. If I get lost, someone will help me home. If I walk in front of a bus so be it let nature take its course.*

*We put Mum's physical safety ahead of her freedom. She is now in a Care Home.*

*We felt we had no choice.'*

([forum.alzheimers.org.uk/showthread.php?63715-Risk-averse-carers-hasten-dementia-decline](http://forum.alzheimers.org.uk/showthread.php?63715-Risk-averse-carers-hasten-dementia-decline))

### *My Mother's Baking*

*She was standing on a footstool in the kitchen when I arrived, reaching up to lift out the multitude of baking trays and put them in a cardboard box, ready for the car boot sale. A few new ones, barely used, but mostly with blackened edges which are now indelible to being washed away. How many cakes had those tins held, how many times had I relished the cakes, my mum's cakes. There were none better, and all our friends knew it, gathering as they did around the table whenever they visited to play. 'Much better now' my sister said, stepping down from the footstool, 'they are just gathering dust up there'.*

*I found my mother in the living room, sitting quietly, barely acknowledging my arrival. She seemed so small. I can't remember when, or even why, we decided my mother didn't need her baking trays any more. Certainly she had not used them for a couple of years now. So what was the point of keeping them.*

*But in the kitchen something was changed, spaces where there were once the things that made up my mother's life. I took one out of the box and put it into the newly formed space. 'What's the point of that?' challenged my sister, 'it looks just silly there on its own! Either none are there or they have to be all be there, one is just pointless'. One cake tin was never enough for my mother. And so my sister and I quickly filled the space back up with all the tins, as though embarrassed by its emptiness, and grateful that our mother, sitting in the room next door, probably didn't realise that we had for a moment made a hole in her life.*

## Ways of Working with Risk

Alaszewski et al. (1998) identified three primary ways in which health and social care practitioners respond to differing understandings of risk:

- Risk is considered to be a hazard
  - and the practitioner is a hazard manager
- Risk is considered to be potentially empowering
  - and the practitioner is a risk facilitator
- Risk is considered to be a dilemma
  - and the practitioner is a dilemma negotiator

The participants in the Genio workshop identified ways in which their role requires them to adopt all of these three positions at time:

As a hazard manager, some of the examples identified were:

- 'Providing training for Home Care workers to prevent any risk to themselves and to the person with dementia'
- 'Risk of fall and incontinence'
- 'Removing medications from person's house'
- 'Support Staff identify risks and put controls in place, Carers to assist with personal (care) etc. eg. support to carry out a "risky" task'

As a risk facilitator:

- 'It is always part of the role is to find solutions which are person centred/practical to enable the person to "circumvent" risk perceived by other people'

- 'Ensuring parties are aware of risks involved and working with that activity with that awareness in mind'
- 'Matching the person with dementia's need with services'
- 'Bathroom assessments - assessing risk at home such as use of equipment (hoists, seating etc)'
- 'Allowing people to keep doing things and taking a chance. Providing aids and appliances to facilitate, for example, a stairlift or a level access shower'

As a dilemma negotiator:

- 'Locking the doors keeps the patient locked in. But which is safer: risks of intruder or risk of fire'
- 'Liaising with other professionals, families, person with dementia'
- 'Family vs personal freedom. Working to support consensus decision'
- 'Discussions with families and the person with dementia about care options. Helping people to understand possible risks e.g. from driving'

Some developments require staff to adopt more than one position of course. For example, one participant identified being both a risk facilitator and a hazard manager in 'rolling out environmental changes to allow people with dementia to access the acute hospital safely'. All participants felt that they had at least two ways of working with risk in their roles.

The key issue is to be clear of one's role and which role is being adopted at any one time. By understanding better these three ways of working, it may be possible to support other staff to see different ways of working too. For example, if you are working as a risk facilitator but someone

else in the team or family are taking the position of a hazard manager, this may exacerbate tensions between what people think is the 'right' thing to do – but encouraging the hazard manager to adopt the position of a risk facilitator may help reduce some of the tensions.

Another key way of working with risk is to consider both the 'hazard event' and the wider context – and the wider context is both over time (past, present, future) and what surrounds the risk event (see Figure 1).

If we consider only the 'hazard event' – let's take the example of Jill going out for a walk – we will tend to see the potential harms (getting lost, being robbed, being hit by a vehicle etc). If we consider the context over time, we will see that Jill has always walked down the road to the postbox to post letters to her daughter. It is something that is important to her

and helps to maintain her social links and reinforces her sense of being a parent. If we consider the immediate context, we will see that Jill is well known by people on her route to the postbox and the only road she has to cross is a quiet lane. Considering the wider context helps us to see what would be taken away from Jill's life if she did not go out for the walk (as a mother writing to her daughter), and assess the likelihood of getting lost or injured. We could also think of some strategies for reducing hazards if they remain a concern – for example, her husband Jack could accompany her across the lane.

In the example earlier of the baking trays, the hazard event is that objects are perceived to be unnecessary, but the wider context illustrates the significance of the baking trays to the mother as a life-long baker, and the likelihood of being harmed by the baking trays is (very!) minimal.

**Figure 1: The context of a hazard event**



## Silent Harms

The examples above – and you will be able to think of many yourself too – show just how easily we take things away from people. Our concern for physical safety can unwittingly take away of some of the purpose in people’s lives (diminishing their quality of life). We can call these ‘silent harms’ (Clarke et al. 2011b) and there are echoes found in the ‘malignant social psychology’ described by Kitwood too (1997). Titterton (2005) argues very strongly against managing risk by attending to physical safety only, arguing that it can lead to:

- Ignoring other needs
- Denying right to choice and self-determination
- Loss of a sense of self-esteem and respect
- A form of institutionalisation with loss of individuality, volition and increase in dependence
- At its worst, can lead to abuse of vulnerable people.

Let us try to explore some of the dynamics that make this such a complex area of practice.

Firstly, it is easy to see people with dementia as being without a future – the popular and academic media have been full of messages about being ‘socially dead’ (Cox and Watchman 2004) and people talk of someone being ‘gone’ or ‘I’ve lost them’ whilst the individual is still physically alive, or ‘what is the point in visiting, they don’t know who I am any more’. By not attending to the future life of someone with dementia, it becomes of little consequence to attend to things that add to the wellbeing of older people: re-narrating life,

social networks, having a purpose, finding a meaning to day to day life: ‘We should not let words rob people with dementia of their life story, their humanity, and a life yet to be lived’ (Sabat et al. 2011).

Secondly, we can tend to view people with dementia as vulnerable – either in themselves or as a result of their social or physical environment. They can become someone ‘at risk’, and this triggers actions within a family or services or wider community that may include a heightened level of surveillance, altered freedoms and even an altered place of living. As discussed earlier, this may be a very appropriate response to protect someone, but may be inappropriate if assumptions of incapacity are made and if there are no measures to support the person with dementia to have a voice in decision-making. In one study, for example, one participant spoke of how he now related to his partner with dementia: ‘I have taken over her thinking’ and his perceived need to ‘check up on her’ (Clarke et al. 2010).

Thirdly, people with dementia (and their families) emphasise their continuing biography and have a sense of their history. They are seeking information that reinforces a sense of who someone is – they are past and biographically referenced. Practitioners on the other hand, know of dementia and other people with dementia. They do not know someone’s individual biography, and are seeking information (assessing) that informs someone’s progression or future with dementia – they are future and dementia referenced. These differing knowledge bases and time orientations can lead to very differing expectations of care and misunderstandings between services and families they care for (Clarke and Heyman 1998). We can see how this dynamic influenced greatly Mary and Fred’s experiences of receiving services.

Fourthly, people's perspective on life changes over time and their desired life outcomes adjust to their circumstances. One study of older people (without dementia) in four countries (Moyle et al. 2010) found that older people experienced loss of influence and power in society, loss of respect and loss of physical abilities but had a strong concern for the welfare of their society and personal aspirations for self-determination. The words of the carer forum earlier reflect the generational tension between the mother's wish for self-determination even at the cost of physical wellbeing but the daughter's concern to maintain physical safety but recognition that this was at the cost of self-determination. It is, therefore, always essential to ensure that the objectives and outcomes wanted by the individual older person are known and considered, and that assumptions are not made that 'our' (often younger generation) views are those of the individual themselves.

Participants in the Genio workshop identified many ways in which silent harms could be prevented and these can be grouped as follows:

- **Respect:** 'Listen to the person with dementia', 'Remember the person as they always were and are and continue to be' and 'Take a step back, do not assume responsibility for the person when they can make their own decisions even if you don't agree with the decision'.
- **Meaningful support:** 'Try and let them remain as independent as possible, remember they still need to feel wanted' and 'Keep doing what the person used to do i.e. gardening, washing etc. Attempt to keep to person's routine prior to dementia as much as possible'.

- **Be informed:** 'Seek out information on stages of disease and the disease process' and find out about the person's life.
- **Least restrictive care:** 'Better to allow freedom and independence than "over restrict" activities. Take a chance if quality of life is improved' and 'Be realistic about risks. It is not possible to eliminate all risks – the focus should be on the least restrictive care and environment'.

There are some key aspects that can help to support quality of life through positive risk taking:

- Enable people to manage uncertainty rather than create certainty - to avoid unnecessary dependence and risk avoidance
- Effective advocacy of the views of the person with dementia – involve them in decisions about risk taking or risk avoiding
- Ensure that assessment includes psychosocial and emotional wellbeing as well as physical safety
- Ensure that there is good communication within and between services.

It is useful to remind ourselves of the words of Carson and Bain (2008):

*'Quite simply, risk taking is sometimes a duty. Not taking a risk can be bad professional practice. Often the real problem is that too few, not too many, risks are taken.'* (p.36).

## Assessing Risk – Process and Outcome

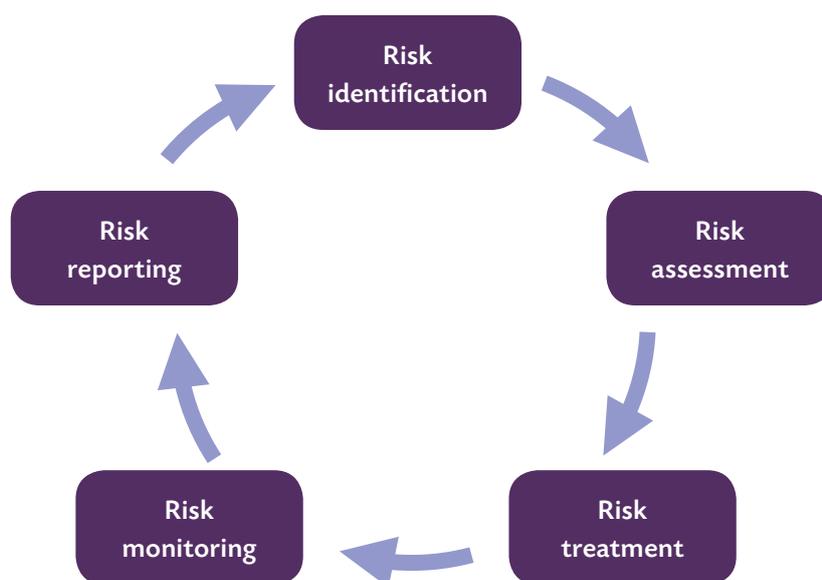
Understandably, many practitioners are worried about their legal position when assessing risks, especially if colleagues and their employing organisation appear to be more cautious and risk averse. There are a few principles that are important to take into account (see Carson and Bain 2008, Clarke et al. 2011b):

1. When undertaking a risk assessment, the law may specify the criteria to be taken into account.
2. The law requires you to consider whose values are to be taken into account in assessing risk.
3. Consider your own professional responsibility under the law of negligence and your professional code of conduct: make decisions and act in a way that is demonstrably consistent with what a responsible body of your colleagues would do.

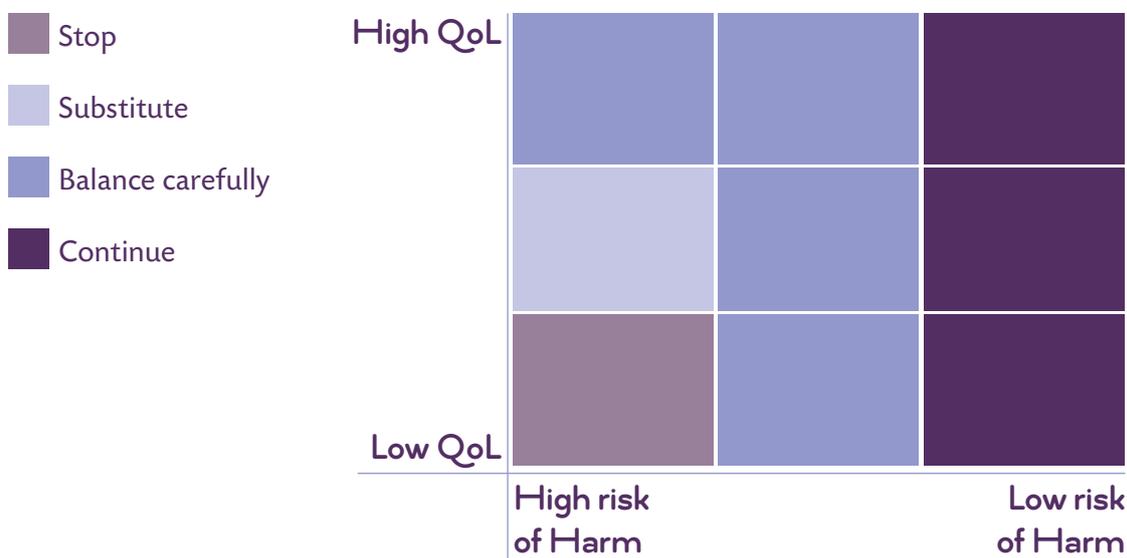
In assessing risk, it is important to emphasise the process of risk assessment, not only see the outcome as important. A good risk assessment process will have collected information thoroughly from a range of people involved (including of course the person diagnosed with dementia); will have considered relevant options; and sought a consensus decision. Remember – it should be very well documented!

However, risk assessment is only one (albeit key) aspect of a cycle of risk management, and it is important to ensure that arrangements are in place for all aspects of the risk management cycle. This learning paper focuses primarily on risk identification and risk assessment, but, as in Figure 2, 'risk treatment', 'risk monitoring' and 'risk reporting' are key parts of the risk management cycle too.

**Figure 2: Risk management cycle**  
(adapted from Health Information and Quality Authority 2013)



**Figure 3: Personal Risk Portfolio**  
(adapted from Department of Health 2010)



Clarke et al. (2011b) proposed the following steps to guide a robust risk assessment framework which emphasises some of the aspects that we have discussed in this paper earlier such as the importance of context:

1. Identify risks in the life-context of personal biography & everyday life
2. Identify risk perspectives
3. Weighting of risks
4. Identify current and past strategies for managing risks

This framework can be used alongside a very useful approach advocated by Department of Health (2010) in which a 'hazard event' is assessed and management responses range from continue unchanged to substitute for a different activity (but which has similar meaning and purpose to the person) to stop the activity (see Figure 3). This is a practical framework to guide decision making and balance risk of harm

with quality of life gain. For example, the only type of activity which would have an 'immediate stop' is one in which there is a high risk of harm and a low quality of life return for the person (i.e. the black box in the figure).

For example, if we think of Jack who was introduced earlier, who is worried about Jill going out for a walk on her own, we might want to consider balancing carefully or substituting (perhaps walking to the postbox together with someone else). Participants in the Genio workshop had several ideas too of activities that could be continued, balanced carefully, substituted or stopped:

- Driving – balance carefully or substitute by getting a local bus or the family could drive
- Going to the Pub – find a way to continue this as it is important for social networks

- Walking dog on busy road in rural area – continue but consider a walking companion and signage on the road
- Wanting to walk a lot from day centre alongside a very busy road - balance carefully with Health Care Assistant going with the person for outside walks
- Wanting to drive to the village for company more than anything but consensus is that it is unsafe – stop and family arrange substitute driver to allow the person to go to Mass every day and do a weekly shop
- Being locked in by family causing poor quality of life - balance carefully and provide education for the family
- Burning pots, forgetting cooker is on – balance carefully and allow to continue by providing telecare and cookerguard

## Conclusion

Risk identification and risk assessment are some of the most complex aspects of professional practice. There is a responsibility to protect yet not diminish someone's quality of life. What positive risk taking enables is a focus that addresses safety AND quality of life. But it does require us to take a broad view of subjective risk and ensure that everyone, especially the person diagnosed with dementia, has a clear voice.

*'There is a delicate balance to draw between empowerment, safeguarding choice and managing risk.'* (DHSSPSNI 2010)

Let us conclude this learning paper with the invitation to reflect on your current practice – as one workshop participant said, this is about the 'sustainability of the person in society'! And most importantly, we need to work with communities to assess and manage risk in a positive way and not to shut down people's futures.

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## Notes

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**Genio**

Marlinstown Office Park  
Mullingar  
Co. Westmeath  
Ireland

T: 044 9385940  
E: info@genio.ie

[www.genio.ie](http://www.genio.ie)



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